#### REPORT TO THE TWENTY-THIRD LEGISLATURE STATE OF HAWAII 2005

AN ANNUAL REPORT ON THE ACTIVITIES UNDER THE NEUROTRAUMA SPECIAL FUND AS PROVIDED UNDER CHAPTER 321H-4, H.R.S

PREPARED BY:

STATE OF HAWAII DEPARTMENT OF HEALTH DECEMBER 2004

#### **EXECUTIVE SUMMARY**

In accordance with the provisions of Chapter 321H-4, the Department of Health is submitting an annual report on the activities of the neurotrauma special fund.

The neurotrauma special fund was established in 2002 by Act 160 for funding and contracting for services relating to neurotrauma. Funds are acquired through surcharges on traffic citations (speeding, drunk driving, not wearing seat belts, leaving the scene of an accident involving bodily injury) that are related to causes of neurotrauma injuries.

Effective January 1, 2003, surcharges from the specified traffic citations were deposited into the special fund. The Department of Health (DOH) is working with people with neurotrauma injuries and their families to identify priorities for expenditure of monies in the special fund. The prioritized need is for assistance to access services and supports (support coordination). Procedures have been developed by the Judiciary and the DOH for transfer of monies into the neurotrauma special fund

The DOH has also established in compliance with Act 160, a Neurotrauma Advisory Board and an infrastructure "to develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system to support and provide services for survivors of neurotrauma injuries." The Neurotrauma Advisory Board provides stakeholder input into the DOH's neurotrauma activities and advisory recommendations regarding the special fund.

# REPORT TO THE LEGISLATURE IN COMPLIANCE WITH CHAPTER 321H-4, H.R.S.

An annual report on the activities under the neurotrauma special fund.

#### Introduction

Act 160, signed into law on June 7, 2002, mandated the Department of Health (DOH) to "develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system to support and provide services for survivors of neurotrauma injuries." The Act also required the DOH to establish a neurotrauma advisory board and administer a neurotrauma special fund. The neurotrauma special fund started to accumulate monies January 1, 2003. This report provides a status report on the fund for the period of December 2003 to September 2004.

#### **Neurotrauma Advisory Board**

The 21 member Neurotrauma Advisory Board was established, per Act 160, to advise the DOH on the use of the neurotrauma special fund and development of a system of supports for persons with neurotrauma. The Board membership constitutes key stakeholder group representation on a statewide basis and has developed and implemented a strategic plan. Members of the Board are listed in Attachment I.

#### Use of the Neurotrauma Special Fund

Chapter 321H-4, H.R.S. specifies that the neurotrauma special fund shall be used for the purpose of funding and contracting for services relating to neurotrauma as follows: (1) Education on neurotrauma, (2) Assistance to individuals and families to identify and obtain access to services (3) Creation of a registry of neurotrauma injuries within the State to identify incidence, prevalence, individual needs, and related information, (4) Necessary administrative expenses to carry out this chapter not to exceed two percent of the total amount collected.

#### (1) Education on neurotrauma

Funds in the amount of \$20,702 were used in 2004 to co-sponsor and support the participation of persons with neurotrauma injuries to attend the Brain Injury Association – Hawaii conference.

(2) Assistance to individuals and families to identify and obtain access to services

Utilizing a definition of Support Coordination that has been endorsed by the Neurotrauma Advisory Board, the DOH has developed structural features of the service system which includes: eligibility, referral, service planning, service provision and monitoring. DOH staff have met with case management

agencies to obtain feedback on the proposed scope of services for Support Coordination. Feedback and interest in becoming a provider have been positive. The DOH is currently finalizing the scope of services in preparation for a request for proposal (RFP) to fund Support Coordination for survivors of neurotrauma injuries. The target date to begin services is March 2005. It is anticipated that 50 individuals will be served in FY 06 and 90 persons in FY 07.

Monitoring of the Support Coordination services and customer outcomes and satisfaction will be done by the DOH.

(3) Development of a registry within the State to identify incidence, prevalence, needs, and related information of survivors of neurotrauma injuries.

The State Neurotrauma and Traumatic Brain Injury Advisory Boards have formed a joint registry subcommittee to recommend components for a system to identify individuals with neurotrauma injuries. A panel of physicians from the subcommittee have identified ICD-9 codes which would best fit the definition of a neurotrauma injury as defined in statute.

The DOH will utilize monies from the Special Fund to purchase discharge data from the HHIC. Although identifiable information of survivors will not be obtained due to privacy considerations, all data will be uniquely coded. In the future, at a point where the DOH is allowed to obtain "protected health information", HHIC will release demographic information (including names) in accordance with their unique identifiers. This first stage of registry development is anticipated to begin in January 2005.

(4) Necessary administrative expenses to carry out this chapter not to exceed two percent of the total amount collected.

Utilization of funds under this category will be determined after plans are finalized for the prioritized support coordination and registry activities.

Effective July 1, 2003, three DOH positions were funded by the neurotrauma fund to provide for coordination and support for neurotrauma system of supports. Duties include planning and coordination of neurotrauma awareness/education activities, information and referral supports for individuals with neurotrauma and their families, assistance for individuals with neurotrauma injuries to access services, eligibility determination and referral for special funded support coordination services, support to the Neurotrauma and State Traumatic Brain Injury Advisory Boards, grant writing, needs assessment and quality improvement.

DOH Education and Public Awareness Accomplishments 2003 – 2004:

- ➤ Developed TBI Discharge Folders for survivors and their family members. Folders were sent to hospitals statewide to provide to families and survivors upon discharge.
- ➤ Developed Spinal Cord Injury Discharge Folder.
- ➤ Participated in numerous conferences to promote awareness and education of neurotrauma: Tools for Life Exposition, Falls Prevention Conference, Direct Support Worker Conference, Supporting Family Caregivers Conference, SPIN Conference, Prevent Child Abuse Conference and the Hawaii Seniors Fair.
- Conducted informational presentations on the DOH's neurotrauma activities.
- Completed conversion of the neurotrauma website into ZOPE format.
- Researched and provided information to both advisory boards on the topics of registries, support coordination, cognitive rehabilitation and special funds.

#### DOH Neurotrauma Help Line

The Help Line provides screening, intake and information and referral to assist individuals and their family members to access needed services in their communities.

In the period of December '03 to September '04, the Help Line received a total of 270 calls as compared to 201 during the period covering November '02 to November '03. A total of 117 individuals were served as compared to 74 during the period covering November '02 to November '03.

See Attachment II for an example of assistance provided for a neurotrauma injury survivor who called the Help Line:

#### **Collection and Expenditure of Funds**

In the period November 2003 to October 2004, a total of \$700,000 has been deposited into the fund from traffic surcharge collections. During that period of time, \$191,499 has been expended for positions. An additional \$20,702 has been used for educational activities for persons with neurotrauma. As of October 15, 2004, there is a balance of \$660,700 in the Neurotrauma Special Fund. It is anticipated that the initiation of Support Coordination services in March 2005 will cost \$250,000 in FY 06 and \$450,000 in FY 07.

The Support Coordination services will be individualized based upon a person centered planning process and the units of services will be authorized by state staff.

A projected budget for the Neurotrauma Special Fund is provided in Attachment III. The budget reflects activities authorized under Chapter 321H-4, H.R.S.

#### **Summary**

Given the Legislative intent of Act 160, the DOH is continuing its efforts to develop a neurotrauma system of supports to assist survivors of neurotrauma injuries and their families. The Neurotrauma, as well as the State Traumatic Brain Injury, Advisory Boards have progressed in their efforts become an effective advisory body to the DOH. During the coming year, the DOH will focus its efforts to developing and maintaining a neurotrauma registry, increase education/awareness activities and begin utilizing the special fund to assist individuals and families to identify and access needed supports through the implementation of a Support Coordination service.

## Attachment I Neurotrauma Advisory Board Members

	Neurotrauma Advisory Bo	
Board Category	Neurotrauma Advisory Board Member	Title/Representation
Traumatic Brain Injury	Vacant– Hawaii	Traumatic Brain Injury Survivor
Survivor/Family Members	Lyna Burian	Parent of Traumatic Brain Injury Survivor
Spinal Cord Injury Survivor/Family Member	Glenn Morgan – Oahu	Spinal Cord Injury Survivor
	Joyce Arizumi	Spinal Cord Injury Survivor
Stroke Survivor/ Family Member State Traumatic Brain Injury Advisory Board Representative Representative from the Brain Injury Association – Hawaii	Dr. Curtis Tom	Stroke Survivor
	Tony Hunstiger	Chairperson, State Traumatic Brain Injury Advisory Board
	Milton Takara	Survivor of Traumatic Brain Injury
	Angie Enoka	Survivor of Traumatic Brain Injury
Stroke Assn. Or Rep.	Karen Seth	Hawaii Heart Association
_	Scott Sagum – Kauai	Stroke Survivor/Support Grp. Rep.
Private Sector Provider	Dr. Maryellen Markley	Director, All Star Sports and Therapy
	Dr. Peter Rossi	Medical Director, Rehabilitation Hosp of the Pacific
	Fred Fortin - Chairperson	V.P. of Community Relations, HMSA
Trauma Ctr. Rep.	Dr. Gail Tominaga	Director, Queen's Trauma Services
At-Large Members	John Noland	Administrator, Department of Vocational Rehabilitation
	Beth Freitas	RN, Chair of Think First
	John Tomoso-Maui	Maui C&C Elderly Services
	Stella Wong	Catholic Charities, Director of Elderly Services
	Ian Mattoch	Law Offices of Ian Mattoch

#### **Attachment II**

### **Example of Information and Referral Assistance**

An individual contacted the Help Line staff to request assistance in completing service application forms and accessing chore services. Due to his traumatic brain injury sustained 15 years ago, it was difficult for him to read and comprehend instructions. In addition it was difficult to maintain his apartment due to physical limitations. DOH staff conducted a home visit and assisted with his application to the Honolulu Community Action Program for utility assistance which paid his electricity bill for two months. Staff also identified agencies/organizations providing chore services and their fees.

The individual had no money to pay for cleaning services and did not have friends who would help him. DOH staff contacted the Moiliili Lions Club who agreed to help and four members spent one morning moving furnishings around to make the apartment more organized and accessible.

Staff also assisted with the application with the Helping Hands Hawaii's community clearinghouse to help him get clothing and bedding items. Assistance was provided to complete his annual application to DHS for his food stamps which was approved. Also information was provided about the Meals on Wheels program and he was able to obtain lunches, Mondays through Fridays.

In a subsequent period of time, the individual injured his leg and required more assistance to get around. DOH staff assisted with an application for a Handivan pass and obtained the tickets.

The person currently wants to move to a more accessible apartment in a quieter and safer neighborhood. Staff worked with his physicians and the C&C of Honolulu Section 8 program to retain his one-bedroom apartment-housing voucher. Currently, staff are assisting the person to look for another apartment.

Attachment III

Projected Expenditures for the Neurotrauma Special Fund
FY05-FY07

Items	FY05	FY06	FY07
Salaries	211,185	211,185	211,185
Support Coordination	25,000	250,000	450,000*
Registry	20,000	60,000	60,000
Education	30,000	33,000	36,000
Expenses Revenues Net	286,185 <u>500,000</u> 213,815	554,185 <u>500,000</u> (54,185)	757,185 <u>500,000</u> (257,185)
Fund Balance	795,815	741,630	484,445

Note: HCBS Medicaid Waiver for Support Coordination to be considered for FY08. This would decrease support coordination fund requirements by approximately 50%.